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ABSTRACT

This paper describes the feelings and needs of children who have siblings with disabilities from the point of view of a woman who has a brother with an intellectual disability. Eight lessons that adult siblings can teach professionals about the significant, often forgotten, family role they play are outlined, supported by descriptive quotations from people in similar situations. The lessons include: (1) having a brother or sister with special needs can stretch the sibling bond in unnatural, and troublesome ways; (2) the role of an adult sibling of a person with special needs has no clear definition; (3) communication with parents about matters related to the future for a child with special needs is often emotionally charged, if it occurs at all; (4) family caregivers face competing, often conflicting, obligations to the people and work responsibilities in their lives; (5) individuals involved in long-term family caregiving need to be able to depend on the reliability of the other support services their relative receives; (6) advocates and self-advocates require access to information that is current, comprehensive, and user-friendly; (7) siblings typically share a strong drive to maintain life-long connection with each other; and (8) siblings of persons with developmental disabilities express frustration at the lack of opportunities and accommodation society offers to their disabled brothers and sisters. (Contains 18 references.) (CR)

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The Sibling :

A Lifelong Journey of Care

written and presented by Victoria D. Liska
based upon an article by Anne C. Guthrie
"Lessons of Love: Listening to the "Other Children"

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Throughout the years of involvement in service delivery for persons with developmental disabilities,, most service providers have failed to notice the presence of the non-disabled brothers and sisters - the 'other' children - who were always around, but somehow remained invisible. As a sibling of an intellectually disabled brother the dimensions of what that experience meant for me as one of these "other children" is now very apparent. After meeting with many who share this life experience, reflecting on their family stories, and delving into what has been written on this subject, Anne Guthrie in her paper Lessons of Love: Listening to the "Other Children" developed eight lessons siblings can teach 'professionals' about the significant role they play in their families are too important to remain ignored. It's time to bring this important new voice into the professional/family dialogue. Through the sibling experience, our understanding of the lifelong influence of family is expanded and enriched.

Here are eight lessons which can be learned from the siblings:

<u>Lesson 1:</u> *Siblinghood is the longest enduring of family relationships; having a brother or sister with special needs can stretch this bond in unnatural, and troublesome ways.*

I first remember having a sense of special responsibility for my deaf sister when I was three. It was my duty to keep her our of danger and mischief--a seemingly normal responsibility for an older sister. But the responsibility has at

times felt unbearably heavy.....The responsibility I felt for Mindy was tremendous. One year, when my 'baby-sitting' duties involved periodic checking on my sister, Mindy wandered away between checks. After a thorough but fruitless search of the neighborhood, my mother hysterically told me that if anything happened to Mindy I would be to blame. I felt terrified and guilty. I was seven. (Hayden,1993)

Frances is very important, she has been a part of my entire life. Her screams have scared me, her cries have saddened me, her biting and pinching have angered me and her lack of ability to deal with the world puzzles me. It makes me feel helpless and I continually search for answers. (Selma Miller, 1985)

As illustrated in the childhood recollections of these two women, growing up with a sibling with disabilities can be a confusing, frustrating and worrisome experience. Although many times forming the basis for a rich, warm and loving bond which provides an understanding of life's many dimensions, the presence of disability can throw this family relationship off balance in multiple ways. Sibling rivalry is a very different experience when your rival can't participate as fully. Somehow you always feel guilty for even trying to compete for attention, love and affection. Moreover, no matter how satisfying or difficult the childhood relationship is, this is one relative who seems to 'never go away'. One who remains tied to the family, yet can't as effectively engage in such typical family functions as providing mutual support, or sharing in the resolution of family problems or conflicts. The growing realization is that you are the most likely candidate to take over your parent's role as primary advocate for your dependent brother or sister can become a

constant factor in your view of the future. I know personally that my choice of a career was based upon the compelling need to be strong both emotionally and economically in order to handle my brother's future needs.

Lesson 2: The role of an adult sibling of a person with special needs has no clear definition, except as a standby, readily available if called. Even then, each assigned role varies with the nature of each new situation.

Adult siblings often express frustration at the difficult position of being in a role that has no formal recognition, and possesses little power. This is especially felt in their dealings with other members of the network of support surrounding their brothers and sisters - most significantly their parents and the professional community. I often felt like a 'shadow caregiver' to my brother. I was to stay in the shadows until called upon when needed. The responsibilities could range from expressing an opinion as an ambassador without portfolio to the critical life decisions necessary from one playing the part of benevolent dictator. When my parents were alive, they made all the important decisions on my brother Joseph's behalf. My opinions while frequently voiced while sometimes considered, they rarely affected their plans. Now that they are deceased, I have assumed legal guardianship for my her brother, Joseph. When I'm attending 'parent meetings' at his residence, I never feel my relationship as a sibling is considered as important to the staff as is that of the parents. I feel I never measure up to the powerful role of the parent . Siblings, it seems, feel compelled to defer to their own parents when

functioning as 'assistant' caregivers, and are taken less than seriously as 'real' advocated in their dealings with service systems when they assume the role of primary caregiver, or even as legal guardian.

Another factor in the ambiguity of their role is the scarcity of attention that have been given to the nature of the adult relationship between siblings by social scientists (Rosenthal, 1992). Inhabiting what has been described as a "twilight zone of family relationships", siblings have "no clear-cut patterns of behavior ...no prescribed ways of relating- no relationship at all, sometimes, since as freewheeling adults theirs is a voluntary relationship" (Slade, 1991). I tend to disagree with that quote from Slade as it is not quite voluntary relationship , I believe there are certain moral and ethical aspects which moves the balance away from the voluntary and more towards the involuntary side of the equilibrium point. The impact on families of such pressing contemporary issues as eldercare support, and chronic and terminal illnesses such as cancer have caused many adults to call on family members for support. The potential of siblings to serve as potential caregivers has now made this relationship a more important area of interest.

Lesson 3: Communication with parents about matters related to the future for their children with special needs is often an emotionally charged exchange, if it occurs at all. Families benefit from, and often rely on, professional guidance in dealing with ways to address the future.

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The day that my mother was diagnosed with pancreatic cancer I became the parent of my parent. The day my mother died I became, for the first time, a parent to my 45 year old brother. The most frightening feeling growing up was...what will I do if something happens to my parents? For years I have asked God to take my sister before my parents. (Itzkowitz, 1990, p3)

Parents are often reluctant to face the need for futures planning, as it forces them to confront their own mortality (Heller & Factor, 1993). Many siblings who assumed junior caregiver roles in childhood find themselves unable to raise the topic and risk causing discomfort for parents who they feel need protecting form additional stress. The stigma of disability in a family has also, for many years, made open and honest dialogue difficult, even in the family home.

Kathryn Edmundson, the sibling of a man with multiple disabilities who has facilitated a unique and effective self-help support group for adult siblings, has observed that:

Siblings...have a unique perspective, made up partly of responsibility, ambivalence, and the sense that they too should have choices... In some families, notably troubled ones, it has been recognized that one member is a sort of "truthsayer" who, by observing and declaring metaphorically that the emperor has no clothes or that yes indeed there is a big pink elephant sitting in our living room, jeopardizes the way the family is used to operating. Siblings of people with developmental disabilities often play that role. (1985)

Even more common, it seems, is the pattern of reliance on unspoken family assumptions. As one father of three children, the youngest of who is a young man with mental retardation, explained:

I guess without discussing them, we do have expectations or beliefs about our kids. We hope they will remain involved with one another as long as they're alive. We have assumed that our kids would look after Johnny when we're gone. That's the way it's been with our own families. We're there to share the good times and help with the bad times. We've been pleased about how well we've all gotten along. It hasn't always been a very good situation for any of us, but .....we've got a good family. (Anonymous father, 1995)

At times of transition, however, assumptions can lead to painful realizations. This father's oldest son has been a caring brother, and agreed that he had always envisioned assisting his younger sibling in the future. Now a law student considering career options, he finds these plans in conflict with his new goals and interests:

When I started college, I assumed that I would stay in the city that I'm living in right now. But I want to give myself a change to see the rest of the country, visit other places.....I say to myself sometimes, life is too short to lock yourself into one place. But then I say, if I move, what will it mean to John, what will happen to my relationship with Julia (his sister).....Lately, I've been thinking my parents are to blame for making me stay in this area. Then I start blaming my brother. Then I think about what will happen to me. I realize I'm becoming independent of my

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whole family, my parents as well a Julia and John.....What kind of a life does that leave me? I find it very confusing.....very disturbing. (Anonymous son, 1995)

Siblings raised with a strong ethic of family loyalty, who share parental skepticism of entrusting non-family caregivers with the care of dependent family members, often make promises- spoken or unspoken- for levels of future involvement they later regret.

Sibling caregivers find that they, too, must confront their own aging and form plans for their brothers or sisters for a time when there are no relatives left to continue providing family care. My own aging has forced me to make compromises in the plans I originally set for my brother, often it is easy to postpone these choices when you are young and healthy and plan to live forever.

Lesson 4: ***Family caregivers face competing, often conflicting, obligations to the people and work responsibilities in their lives. Attending to their own needs, in contrast, feels uncomfortably selfish.***

Establishing healthy boundaries within families is difficult and I contend that doing so in a family with a member who is intellectually disabled borders on the impossible without experiencing emotional trauma coping with the conflicting feelings of loyalty to the family and the family needs and the overwhelming need for independence.

Lesson 5: **Individuals involved in long-term family caregiving need to be able to depend on the reliability of the other support services their relative receives. The well-being of all family members is jeopardized by the impact of inconsistent, reduced or eliminated supports, especially when a person's disability limits their capacity to adapt to, or cope with, change.**

I worry about my brother many times during the day and I confess in the darkness of the night I pray that I may outlive my younger brother so that I may continue to advocate for him during his lifetime. This is so, not matter how good a facility or the staff may be. I contend that nothing can take the place of the love and caring of family members.

Lesson 6: ***Advocates and self-advocates require access to information that is current, comprehensive and 'user-friendly'. Additionally, support groups and professional consultants have been found to be significant sources of help in the problem-solving process.***

Emotional readiness must be acknowledged and nurtured by the family services professionals. Service providing is not one sided, it is a collaborative effort of the family members and the professionals. Within the last six months, Don Meyer has established the SibNet on the Internet, which allows non-disabled siblings to share concerns, feelings, fears and problem solve with others in a worldwide forum.

The Internet address for the SibNet is http://www.chmc.org/departmt/sibsupp. This is in addition to support groups such as that sponsored by the AHRC-New York City which has been in operation for over fifteen years.

Lesson 7: ***Siblings, no matter what their level of capability in other areas of life, typically share a strong drive to maintain life-long connection with each other. Although the relationship may be a troublesome one, it persists as a part of the shared heritage of their childhood.***

Despite their possibly diminished capacity to reciprocate as fully as other siblings, persons with disabilities find their relationship with brothers and sisters to be important and meaningful. The forced 'parentification' of a more able sibling can, however cause a strain in what normally is a more equal relationship.

My brother with Down's Syndrome, has been electively mute for more than twenty years, yet he has facial expressions and expressive body language which would rival some of the best of Hollywood actresses and actors. This is not always initially apparent, but many teachers and other service providers have confirmed this personal observation. Many times when I would indicate the special communication methods I have with my brother, I have noticed the skeptical reactions of the service professionals.

Lesson 8: **The final lesson. Siblings of persons with developmental disabilities express frustration at the lack of opportunities and accommodation society offers to**

their brothers and sisters. The President's Committee on Mental Retardation highlights many issues currently confronting people with developmental disabilities, their families and advocates, poses a challenge for America's current domestic reform agenda, in stating:

We stand at a crossroads in the nation's passage into the 21st century. Long-standing assumptions about the relationship of government and citizen in health care, education, employment, and social welfare are being challenged.

The choices made in this national debate will have profound implications for persons with mental retardation. Like a mirror held before the national renewal effort, the success of reform will be reflected in their lives and well-being (p.1).

If the professional community reflects on the important message for service delivery found in the lessons taught by siblings of persons with special needs, we might, as a nation, come closer to achieving the goal of inclusion of all of our citizens. On behalf of the "other children", and the families they love, please listen more carefully to these often unheard, but significant voices. It is not enough to hear the facts, it is just as important to listen to and interpret the message of love and care.

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